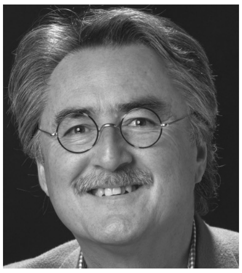
Bereavement care for the non-bereaved

A health promotion challenge



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Abstract: This article outlines key approaches for a health promoting approach to end-of-life care. Although direct service provision for end-of-life care and bereavement are crucial to any public health approach to dying, death and loss, a broader public health approach – one that targets people in good health and outside acute episodes of need – is also vital to building a community's capacity for resilience and self-care. The approaches described in this article include community development, death education and social marketing, partnerships between statutory services and communities, local policy changes and critical reflection. International examples of these approaches are described with the aim of stimulating discussion and debate about their potential and worth in bereavement care.

Keywords: End-of-life care, health promotion, public health, bereavement, community

At first, the idea of bereavement care for the non-bereaved seems a paradox. We do not routinely provide bereavement care to someone who does not feel that they are directly or indirectly bereaved. But then, before the development of the 'new' public health (or health promotion) in the 1970s and 1980s, most health care systems in the world were designed to care only for the sick, disabled or dying – to intervene during illness and disease, not to promote health at all. The notion of providing 'health care' to the healthy was simply not thought of.

However, early intervention and preventative thinking now permeates primary health care services as well as our broader health policy. Most people now understand – through a combination of public education, social marketing campaigns and occupational, industrial, health and safety laws – that health is about much more than direct services to treat sick people. Many of our modern ills – cancers, heart disease, diabetes and even accidents – are amenable to prevention or harm reduction strategies in workplaces, schools and our own homes. We are able to exercise a degree of control over the social determinants of health and illness – diet, drug and alcohol use, physical activity, exposure to pollutants, safe environments, condom or safety helmet use, and so on.

In end-of-life care, an understanding of the determinants of social and psychological health for people living with a life-threatening illness or bereavement has been a far more recent phenomenon.

This article provides a brief review of recent developments in health promotion for end-of-life care and identifies implications for bereavement care policies and practice. Our aim is to offer readers unfamiliar with public health developments in end-of-life care some basic pointers for thinking about bereavement care in these new, emerging terms. Although many of our examples describe palliative or aged care interventions, the main point is that all of these health promotion initiatives target the general population to increase support for the dying or elderly. In this way, we hope to provide a stimulus for thinking about enhancing support capacity for bereaved people by encouraging this 'population health' approach – encouraging the wider, general population to take greater responsibility for their own self-care and the care of others living with loss.

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Health promotion in end-of-life care

In palliative care the longer part of dying actually occurs outside episodes of direct service provision and professional care (Dudgeon *et al*, 1995). After disclosure of a limited life expectancy (prognosis), many people with a life-threatening illness are able to continue for some considerable time to engage in their usual occupations – in work or play. Their main important relationships will continue to be with friends, family and work colleagues.

The 'quality of life' for these people – the ability to avoid or combat social isolation, stigma, ignorant responses, the stress of caring and the continuation of 'normal' family, community and work tasks, even in the terminal phases of their illness – crucially depends on these relationships. However, the capacity of these relationships in community, neighbourhood and household may itself depend on wider support and partnerships with professionals, government, churches, workplaces or schools (Kellehear & Sallnow, 2009).

Information, education, formal partnerships with other services or simply other people willing to help, as well as local health or workplace policies, can improve the life of people living with life-threatening illness and those caring for them. Palliative care services in the US (Rao, Anderson & Smith, 2002; Rao *et al*, 2005), India (Kumar, 2007), Australia (Kellehear, 1999, 2005; Sala, Rumbold & Young, 2007) and Japan (100-Member Committee, 2007) have formed partnerships with a diversity of 'non-health' services and institutions to supply such supports for communities and families. These developments are also now strongly emerging in UK end-of-life care services and policies (see Russell & Sander, 1998; Monroe & Oliviere, 2007; Conway, 2008; Scottish Partnership in Palliative Care, 2008; Sallnow, Kumar & Kellehear, 2009).

Sometimes, volunteers have played a central role in providing education, informational and practical supports in these services. This has been a long-standing, early example of health promotion. But many (although not all) volunteer 'services' from hospices are not sustainable: they rely, for example, on the management presence, organising ability and motivation of the local hospice service for their establishment and continuity. If the local service were to close, so too would the volunteer services associated with the hospice. Health promotion requires education and support to be autonomous and self-supporting within the communities that foster them – they are required to have 'sustainability'.

The key approaches to health promotion in end-of-life care are as follows.

Community development

In Australia, palliative care services have been re-orienting their approach from working *on* communities (fundraising, hospice awareness campaigns, didactic approaches to death education, volunteer recruitment etc) to working *with* communities. Working with communities requires a participatory approach to relationships – working alongside business, schools or workplaces to help them identify issues about death, dying, loss or care that are important to them. After the identification of these priorities – which may not be about, or may not be solely about advanced states of ill health and disease but about, perhaps, grief, dementia care, or suicide, for example – ways and methods to address these concerns are developed. Hume palliative care service in Australia is an example of this (Kellehear & Young, 2007).

Hume palliative care service was a two-year practice project funded by the Australian federal government in 2004. The aim of the project was to build community capacity for supporting people living with dying, loss and caregiving. Initially led by the service itself, the project was a partnership with existing local primary care, hospital and community health and home care staff. Evaluation of the effectiveness and sustainability of the project was conducted by a local university public health research team. The results showed the project to be successful in engaging the community in taking a more active role in caring for those living with life-threatening illness, loss and caregiving for both. The project has continued, with professional, community and financial support, beyond the original funding period. Developments initiated by Hume in partnership with other community organisations but now operated solely by those organisations include courses for carers run by an adult education centre; art exhibitions and dramatic performances on loss and grief; 'World Café' community discussions about death, dying and loss; development by local councils of reflective spaces in cemeteries for families who have died in palliative care services; information stands and life education programmes run by local church groups and the Alzheimer's Association at festivals and horse races, and local 'care for the carer' days organised by local shops and businesses.

Death education and social marketing

Just as health education is an important resource for people to understand which elements in their lifestyle are unsafe or harmful and which safeguard health and well-being, death education can provide similar guards against harms while promoting health and well-being. Going to a hospice for an 'information' night is not attractive to many people. There are many ways to 'sell' the important health messages that are crucial to the care of people living with a life-threatening illness – the usefulness and importance of listening for people who are stressed by caregiving or grief; the importance of staying in touch with colleagues or friends whose health may be worsening; the value of talking about advanced care directives or making wills before they are needed, and so on. Such ideas can be discussed in a variety of forums and using a variety of media – from short story competitions and talk-back radio programmes to trivial pursuit nights. Newcastle palliative care service in Australia (Kellehear & O'Connor, 2008) is an example of this.

Saying the Unsayable was a community awareness-raising project organised in Birmingham by NHS West Midlands strategic health authority as part of its Health Promoting End of Life Care strategy. The aim of the event was to 'open a dialogue about living, dying and death'. Eleven community groups were invited to produce photographs on the project's main themes of living, dying and death, and these were exhibited in a specially built dome in Birmingham's central Centenary Square. The event also included performance art with opportunities for passers-by to tell their own stories of people who had been important to them and create their own temporary memorials. See www.wellbeingindying.org.uk

The Newcastle palliative care service was initiated by a volunteer group of hospice nurses, doctors and social workers, who met regularly to read, discuss and initiate health promotion projects for their local community. It was guided by some initial training and support from the palliative care unit in the La Trobe University school of public health. Simple evaluations of many of the activities, including their support for school policy changes for death and loss, were conducted by the group and these showed considerable positive changes in behaviour and attitudes toward death and loss in these communities. The project is ongoing.

Services and community partnerships

If normalisation of death and loss is to be restored so that people can begin to talk about these matters with less avoidance, fear and dread, then we will need partners who are not simply end-of-life care specialists. Although palliative care staff know a great deal about death and loss, community health colleagues (for example) know a great deal about community development, health education and social marketing methods. Partnerships with these colleagues enable a sharing of experience and skills that brings death and loss within the public health campaign remit, alongside other harm reduction and health promoting efforts around drugs and alcohol, child safety, bullying, domestic violence and sexual behaviour.

Two recent examples from the UK are St Joseph's and St Christopher's hospices in east and south London respectively, who have usefully formed innovative health promotion programmes in partnership with patients or local communities. St Christopher's Hospice has employed the creative arts – music, poetry, art, photography and even fashion design – to enhance patients' health and well-being at the end of life (Hartley, 2007). St Joseph's Hospice has developed long-standing relationships with the local Somali and Bengali communities to enhance and improve their social, pastoral and medical care of people dying from heart failure (Richardson, 2009).

In 2004, a coalition developed and led by a government department in Japan decided to implement a health promotion strategy for elderly people living with dementia. The coalition consisted of local businesses, academics, trade unions, welfare, medical and health organisations. These organisations comprise the 100-Member Committee to Create Safe and Comfortable Communities for People with Dementia. The committee, which is still in existence, organises a national annual competition to encourage communities to come up with their own best ways to help people living with dementia. The many successfully evaluated initiatives include social partnerships between schools and dementia care facilities that encourage increased interaction and participation between the elderly and the young in sports days, nature-learning days, and even in the provision of elderly-led safety patrols for young school children on their way to and from schools. Village high-street businesses have also volunteered to provide modest hours of day care or respite care on their premises for families caring for people living with dementia. This has not only increased the availability of the support for people living with dementia and those caring for them but has also helped to 'normalise' the presence of people living with dementia in the many public spaces in the participating villages. The projects are ongoing and spreading (100-Member Committee, 2007).

Local policy changes

It is important that we change the environment or cultural climate of the places where we spend most of our time – schools or work, clubs and pubs – so that promoting health and safety becomes a 'normal' civic responsibility. This is the case whether we are speaking about national policies of health promotion in palliative care (Scottish Partnership for Palliative Care, 2008) or local hospice work with other organisations.

In Newcastle palliative care services in Australia (Kellehear & O'Connor, 2008), for example, relationships with local schools have resulted in changes to school policies on death and loss. The local palliative care team also work with teachers to identify where death and loss might normally arise in the school curriculum and help them to lead reflective conversations with their students at these times. In this way, 'death education' is worked seamlessly into the mainstream curriculum and its topics and concerns.

In Kerala, India, the Institute of Palliative Medicine has established a series of community managed palliative care facilities (neighbourhood networks) that are operated by community volunteers (Kumar, 2007). These volunteers are from all occupational walks of life and, under the initial guidance and training of the institute, perform a variety of support tasks for the dying and their families, ranging from basic nursing and support assessments to transport and shopping for necessary food or drugs. The neighbourhood networks have become so popular and extensive in their coverage that several major social institutions outside medicine and health care have recently become involved. For example, the local police now volunteer to help provide transport to inpatient and respite care services. University student clubs now fundraise and offer their own time to support these activities, as do high school students in the wider community. This has served to change policies in schools, law enforcement agencies and the local media as each of these institutions allows their pupils and workers to be directly involved in end-of-life care.

Critical reflection

Obviously, health promotion initiatives are not confined to community and policy work, forging partnerships, education of the general public, or counselling and the provision of information and support. Critical reflection is also an important means of health promotion. Reflective approaches to counselling people who are bereaved are a common initial and exploratory approach to examining assumptions about relationships, loss or identity. In particularly traumatised cases, such initial explorations might evolve into a deeper psychotherapeutic style of counselling.

However, the initial exploratory processes of critical reflection have additional health promotion value if used with people not currently experiencing grief – with, for example, members of the wider community, volunteers or even co-workers. In this way, critical reflection may be employed as (1) an alternative strategy to counselling, and (2) for an additional population – particularly members of the wider community who are carers, close friends or family of bereaved people.

This is not to discount the need for therapeutic counselling, particularly on a one-to-one basis for people who may be experiencing emotional trauma or distress. However critical reflection, because it derives from learning traditions rather than therapeutic traditions, may provide an alternative approach for people who do not see themselves as in need of more intense emotional support. In this sense, therefore, it might lend itself more readily to use in more public or community domains.

Critical reflection is essentially a learning strategy, and is a key aspect of learning from experience (Dewey, 1933). Although most people learn from experience in an ongoing way throughout their lives, we are often largely unaware of the processes by which we do this, and indeed often of what we specifically learn. Critical reflection, as a process used in health promotion, is a way of identifying and harnessing this learning in order to develop a more sensitised understanding of the experiences we all share, and how they relate to bereavement experiences. In this sense, critical reflection is a way of learning how to incorporate the learning from life experiences, so that bereavement experiences are normalised, and are seen as an integral part of life experience.

How might this be done? One approach to practising critical reflection is to uncover the fundamental assumptions implicit in experience. This enables these assumptions to be examined for their current relevance, and changed (along with the actions or behaviour associated with them) if they are deemed outdated or inappropriate. There are many well-developed methods for doing this (Fook & Gardner, 2007; see also Taylor & White, 2000; Rolfe, Freshwater & Jasper, 2001; Ghaye, 2005).

For example, people could discuss in community education groups, or even in personal conversations, instances when they felt very distressed at the bereavement of a friend or family member, and when they may have wanted to put pressure on that person to 'recover' or show signs that they are coping again. Critical reflection techniques could be used to help participants examine what lies behind their own distress or wish that the person should recover, and what they are assuming about grief and loss. This might reveal an assumption that they will feel better if the bereaved person feels better, or that they don't feel they have helped unless they have managed to staunch the visible signs of grief. A common assumption may be that people are supposed to 'get over' their grief after a certain length of time.

Once these assumptions are identified, it is then possible to examine their validity, and whose needs they may be based on – which may not be those of the bereaved person. It may be possible then to find ways to help bereaved people find their own meaning in a bereavement experience, in which the distress is a necessary element. Critical reflection, in conjunction with a wider health promotion approach, may therefore provide a way to help all people find meaning in bereavement experiences as an ongoing part of life.

Critical reflection in personal conversations or in a group setting might also be used in conjunction with more traditional counselling approaches. People do not usually access or request counselling services unless they have experienced a specific bereavement event. The advantage of critical reflection is that it might be offered in a much more public way, as part of a set of approaches in working with the general community to incorporate bereavement into life experiences.

Implications for bereavement care

End-of-life care is far more than palliative care. Aged care, intensive care, emergency services, disaster management, coronary care and bereavement care, among others, are crucial to how we manage death, dying, loss and care in everyday life. Direct service provision – professional care of people in their hour, day or year of need – is essential but it is not enough. Good health care must be more than the provision of services and professionals. A health promotion approach embedded in local community actions is essential. Workplaces, schools, churches and temples, clubs, pubs, art galleries and museums and shopping malls are among the many places where people can and are able to learn about health, well-being and – ultimately – mortality. Health, as the WHO observes and advocates, is everyone's responsibility.

In this context, bereavement care is also everyone's responsibility (Clark *et al*, 2005). However, until quite recently, much of the work with communities or individuals – including health promotion activities – has been with grieving individuals and communities. Furthermore, that work has often been done by professionals for and to communities and individuals, not in partnerships with local organisations and using their ideas for capacity-building against death, loss and grief. Bereavement care in the context of prevention and harm reduction goals for the wider community is an important and emerging challenge for the future.

An important first step in addressing this challenge is asking what individual bereavement care workers can do in the context of their current jobs, which may not be based on a health promotion approach. Some critical reflection on their current practices in bereavement care is a ready starting point. Are we assuming that there are differences between bereaved and non-bereaved people? Why do we focus our efforts on people who have experienced an identified bereavement, rather than recognising that grief enters most facets of life? Reflecting on these assumptions helps us connect the experiences of the 'non-bereaved' with the experiences of the 'bereaved'. In this way we are more likely to be able to design and implement an approach to care as a community of people who will share bereavement experiences over the course of a lifetime. ■

Clark E, Dawes J, DeSpelder LA, Ellershaw J, Gordon J, Howarth G *et al* (2005). The Tucson IWG charter for the normalization of dying, death and loss. *Mortality* 10(2) 157–161.

Conway S (2008). Public health and palliative care: principles into practice? *Critical Public Health* 18(3) 405–415.

Dewey J (1933). *How we think: a restatement of the relation of reflective thinking to the educative process*. Boston, MA: DC Health.

Dudgeon DJ, Raubertas RF, Doerner K, O'Connor T, Tobin M, Rosenthal SN (1995). When does palliative care begin? A needs assessment of cancer patients with recurrent disease. *Journal of Palliative Care* 11 5–9.

Fook J, Gardner F (2007). *Practising critical reflection*. Maidenhead: Open University Press.

Ghaye T (2005). *Developing the reflective health care team*. Oxford: Blackwell.

Hartley N (2007). Resilience and creativity. In: B Monroe, D Oliviere (eds). *Resilience in palliative care: achievement in adversity*. Oxford: Oxford University Press, 281–292.

Kellehear A (1999). *Health promoting palliative care*. Melbourne: Oxford University Press.

Kellehear A (2005). *Compassionate cities: public health and end of life care*. London: Routledge.

Kellehear A, O'Connor D (2008). Health promoting palliative care: a practice example. *Critical Public Health* 18 (1) 111–115.

Kellehear A, Sallnow L (2009). Public health and palliative care: an historical overview. In: L Sallnow, S Kumar, A Kellehear (eds). *Proceedings of the 1st international conference on public health and palliative care*. Kozhikode, India, 18–27.

Kellehear A, Young B (2007). Resilient communities. In: B Monroe, D Oliviere (eds). *Resilience in palliative care: achievement in adversity*. Oxford: Oxford University Press, 223–238.

Kumar S (2007). Kerala, India: a regional community-based palliative care model. *Journal of Pain and Symptom Management* 33 623–627.

100-Member Committee to Create Safe and Comfortable Communities for People with Dementia (2007). *National roll-out of the campaign to understand dementia and build community networks* [online]. Available from: http://www.ninchisho100.net/english/index.html [accessed 14 July 2010].

Monroe B, Oliviere D (eds) (2007). *Resilience in palliative care: achievement in adversity*. Oxford: Oxford University Press.

Rao JK, Alongi J, Anderson LA, Jenkins L, Stokes GA, Kane M (2005). Development of public health priorities for end of life initiatives. *American Journal of Preventive Medicine* 29(5) 453–460.

Rao JK, Anderson LA, Smith SM (2002). End of life is a public health issue. *American Journal of Preventive Medicine* 23(3) 215–220.

Richardson H (2009). Diversity in heart failure – a community development model of health promoting palliative care in East London. In: L Sallnow, S Kumar, A Kellehear (eds). *Proceedings of the 1st international conference on public health and palliative care*. Kozhikode, India, 9.

Rolfe G, Freshwater D, Jasper M (2001). *Critical reflection for nursing and the helping professions.* Basingstoke: Palgrave.

Russell PS, Sander R (1998). Health promotion: focus on care of the dying. *International Journal of Palliative Nursing* 4(6) 266–270.

Salau S, Rumbold B, Young B (2007). From concept to care: enabling community care through a health promoting palliative care approach. *Contemporary Nurse* 27(1) 132–140.

Sallnow L, Kumar S, Kellehear A (eds) (2009). *Proceedings of the 1st international conference on public health and palliative care* [online]. Institute of Palliative Medicine, Kozhikode, India. Available from: http://www.pubhealthpallcare.in/ [accessed 14 July 2010].

Scottish Partnership for Palliative Care (2008). *Living and dying well: facilitating a national conversation on death and dying in Scotland*. Short life working group. Edinburgh: NHS Scotland.

Taylor C, White S (2000). *Practising reflexivity in health and welfare*. Maidenhead: Open University Press.